Dominic M. Cotton Testimony for HB 6155:- AN ACT CONCERNING THE MEDICAID WAIVER APPROVAL PROCESS.

Dear Human Services Committee,

I am testifying in support of HB 6155, as I am the person who proposed the concept on behalf of a Waiver Community that I have participated as a provider and an advocate over the past 15 years. Below I have outlined my original proposal and the problem history associated with this bill. I want to focus on two key concepts of Person Center Planning and Reasonable Accommodation.

Person Centered Planning as Defined by the Department of Social Services: The key to an individual's ultimate satisfaction and progress in living in the community is person centered planning. Under this model the individual is the essential participant in determining the services he or she may require in order to live safely in the community. The individuals satisfaction with various services provided under this waiver is the primary measure of the quality of those services.

ADA defines a reasonable accommodation is any kind of modification or adjustment to a job or to the work environment that makes it possible for a qualified applicant or employee with a disability to either participate in the job application process, enjoy equal benefits and privileges of employment, or to perform essential job functions. In the case of waiver populations or notification of disabled people, the State of Connecticut should be afforded a reasonable accommodation based upon physical or cognitive needs in order to ensure their participation in a public process.

The Department of Social Services requires person centered planning in providing services for participants in the ABI waiver, the federal government is focused on ensuring that person centered principals are used in all environments where people receive services. So should hold true for the Department of Social Services ensure that person centered planning be utilized in the public process. DSS needs to allow for a reasonable accommodation to ensure that people with disabilities have the opportunity to Self Determination.

Thank you for you time and attention to this Critical Issue

Sincerely, Dominic M. Cotton MHA

Original Bill Proposal

Intended target: Participants and Providers involved in the following Medicaid Waiver Programs; Acquired Brain Injury Waiver, Individual Family Support Waiver, Mental Health Waiver Katie Becket Waiver, Community Supports for People with Autism, Personal Care Waiver, Connecticut Home Care for Elders Waiver, Comprehensive Support Waiver, CT employment and day support waiver, CT HBCS waiver for persons with Serious Mental Illness in Nursing Home Waiver.

Target Problem: Medicaid Waiver participants are not properly notified of amendments or reauthorization of Waiver Programs and subsequent public hearings with regards to these programs. Persons' with disabilities, Program Providers, and family members need advanced notification of changes to programs that their lives depend upon. The State of Connecticut has improved upon the antiquated system of postings in The Connecticut Law Journal and makes postings available on the Secretary of States website. The difficulty is that many persons involved in these programs can't afford internet services, or lack the capability to locate the information on-line. Timely notification of waiver amendments and reauthorization is critical to meeting the federal guidelines for public input into waiver programs, and enhances the level of trust and transparency between government agencies participants, family members caring for or conserving loved ones and providers.

ADA Compliance: ADA defines a reasonable accommodation is any kind of modification or adjustment to a job or to the work environment that makes it possible for a qualified applicant or employee with a disability to either participate in the job application process, enjoy equal benefits and privileges of employment, or to perform essential job functions. In the case of waiver populations or notification of disabled people, the State of Connecticut should afforded a reasonable accommodation based upon physical or cognitive needs in order to ensure their participation in a public process.

Current Law:

Effective July 1, 2013, Sections 9 and 10 of Public Act 12-92, respectively amend Connecticut General Statutes (CGS) Sections 17b-10 and 17b-423, and require the Department of Social Services (DSS) to electronically submit certain new department operational policies to the Secretary of the State for posting online before adopting them.

CGS Sections 17b-10 and 17b-423, as amended, also require DSS to post each new policy to its website. In addition, DSS must publish notice of intent to adopt the policy as a regulation in the *Connecticut Law Journal* not later than 20 days after adopting the policy. CGS Sections 17b-10 and 17b-423, as amended, state that the noticed policy is valid until the time final regulations become effective.

Problem History: In the past two year the Department of Social Services attempted to make massive changes to the Acquired Brain Injury Waiver. In the process they failed to notify any of the participants, instead they went directly to the advocacy

group involved with the program. Many families and program participants caught wind of the proposal and forced DSS to have a public forum. The family members and participants voiced their distress over the change in a unified voice. As a group we felt that the non profit organization that purported to represent program participants had limited reach within the community and frequently requested that providers pay and join their council in order to have their voices heard. The suddenness with which an amendment, and the lack of transparency from DSS mystified our entire community. As a group we lobbied hard against program changes and got many Representatives and Senators to prevent services for our program and subsequent participants receive appropriate services. There were many contentious meetings and public hearings over the new ABI waiver II. The final public hearing brought about the creation of a committee to address issues directly with DSS. In discussions with other participants of other waivers there is a mutual concern that participants have a limited voice in waiver amendments and notice of public hearings.

Bill Mechanics: The process for Notification would work as follow

- 1. Two month or longer prior to a waiver amendment public hearing with a committee of waiver Cognizance, the government agency will send out via mail and e-mail an executive summary of changes to waiver program participants, conservators, and program providers. In addition to the summary will be directions to a specific website for a complete version of all changes. This will be accomplished by the Waiver programs fiduciary agent as they will have all of the proper addresses.
- 2. In addition to the executive summary the government agency will provide an opportunity for all parties to comment on the changes via e-mail or written mail. If a program is to be discontinued or substantially changed a Public Forum should be scheduled in the Legislative office building to gauge the publics reaction prior to any official public hearing to afford lawmakers and the department listen to and change amendments, prior to a public hearing.
- 3. Once the committees of cognizance are contacted and a Public Hearing is schedule the government agency will send out a written notice via mail to all program participants, conservators, and providers via mail and c-mail no less than ten days prior to the date of public hearing.

Recent History in support of the Bill: Recently two new amendments to the Acquired Brain Injury Waiver were put forth by DSS they placed a website with information and an opportunity for public comment, but failed to notify all persons' involved in the waiver. Many people commented upon the proposed amendments and as a result DSS pulled one of the waiver amendments. The announcement of the public hearing happened two days prior to the public hearing and was only given via nonprofit agencies. This limited the public's opportunity to participate and give helpful input to lawmakers on the amendments involved. Two days prior to the public hearing the department sent out a summary of one of the amendments stating this was the direction of program changes even though the changes had yet to be voted on by the joint committees of Human Services and Appropriations. This clearly points to the fact that State Agencies could have done this with adequate time frame but have failed to do so.

Projected Bill objections:

1. The State agencies with oversight of specific waivers might state that it should be advocacy groups that should notify their membership of amendments and public hearings.

Answer: Not all advocacy organizations are focused on the specific issue of Waivers and are more focused on the group as a whole and opinions may not represent waiver participants. Additionally they might require a person becoming a member and paying for the information. Waiver Program participants have limited funds and can't afford to pay for advocacy membership.

2. State agencies might state that it is an added burden to notify people directly

Answer: It is better to have appropriate public input on programs that cost the State Tax Payers millions of Dollars and make appropriate amendments that assist the respective communities. Additionally these programs are being accessed by more and more participants who have the right to self determination and should be afforded the opportunity to ensure services are appropriate for their community.

3. The legislature should not be involved in individual agency procedure:

The legislature has cognizance over specific agencies and is frequently the only body that can intervene upon Agencies to ensure that programs are held accountable from administration to administration